Fetal Cardiology Nurse Specialist

The contact names and details for the Fetal Cardiology Nurse Specialists can be found below:

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The nurse’s role in the fetal cardiology clinic

To offer support and give information and advice on treatment options to families whose baby is suspected of a having a cardiac defect.

Following diagnosis

Following the diagnosis of fetal heart disease a thorough explanation of the heart defect is made to the family, along with a description of the anticipated neonatal course, possible surgical interventions and long term prognosis/outlook. Information is given in a clear non-directive manner in a way that is appropriate for the family’s needs/understanding.

Parents/Families

Following diagnosis there are many feelings parents/families may be trying to cope with:

* Shock. It was probably assumed the baby would be healthy.
* Grief. For the loss of the healthy baby they thought they were carrying and for the baby they are now carrying.
* Anxiety. Worrying about what the results mean for the family and the baby.
* Isolation. They may feel as if they are the only people this has ever happened to.
* Guilt. They may wonder if they did something to cause the problem (though this is highly unlikely).Their feelings about the baby may have changed.
* Confusion. They may be finding it difficult to take in the information they have been given about the problem and their options.

Information, Education and Support

After giving parents/family information about the cardiac problem:

* Allow parents time for questions, to express grief and to be left alone if desired.
* Give them written information to take away with them, including contact numbers and information about relevant support groups.
* Make appropriate arrangements for follow-up. Some conditions have a lot of information available while with others there is very little known. We would offer referral to fetal medicine unit for consideration of further testing i.e. Amniocentesis or Karyotyping.
* 1 baby out of 10 who has a cardiac condition will have problems with other organs or with the genes that are responsible for the development of these organs (chromosomal defects).
* Communicate with local hospital/community teams/GP regarding plans for the remainder of the pregnancy.

Follow up

In continuing pregnancies:

* Offer support during every outpatient appointment and offer phone contact/home visits between appointments.
* Check appropriate arrangements have been made for delivery (local or Leeds).
* Offer appointments to see other professionals.
  + e.g. Cardiac surgeon and/or cardiac wards.
* Neonatologists and/or neonatal unit.
* Geneticists.
* Psychologists/counsellors
* Offer to arrange contact with other parents.

If pregnancy not continuing:

* Referral to community midwife for post delivery care.
* Offer contact pre and post termination and suggest referral for specialist support:
* Hospital psychologists/counsellors.
* ARC (antenatal results and choices). Offer practical advice and individualised support for parents’ pre and post termination.
* Sands. Self-help support group for bereaved parents and their families.

If opting for comfort care:

* Offer care as for those continuing their pregnancies, (though some women choose not to attend all their appointments/have further scans).
* Offer referral to children’s hospice/ paediatric palliative teams for end of life care and support.
* Offer bereavement follow up.